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**Mental Health Services for Children and Adolescents with Learning Disabilities: A  
Review of Research on Experiences of Service Users and Providers**

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Key words: learning disabilities, children, adolescents, mental health services

### **Accessible Summary**

- Many policies and initiatives have been developed to improve the mental health services for children with learning disabilities.
- Children with learning disabilities and their parents, however, experience many barriers accessing mental health services.
- Service providers identified a lack of resources as a barrier to meeting the needs of children with learning disabilities.
- Current research offers suggestions on what can be improved, but further research is needed to identify what models of service would work best for children with learning disabilities.

### **Summary**

Issues: Children and young people with learning disabilities experience high rates of mental health problems. The present paper reviewed the literature on mental health services for children with learning disabilities, in order to identify known models of service provision and what has been experienced as effective or challenging in providing good services. Findings: Children with learning disabilities and their parents experience barriers accessing mental health services that are related to a lack of information and perceptions of services as being inadequate. Service providers identified a lack of resources as a barrier to meeting needs. Although positive experiences are also observed, many parents have found services to be inappropriate or overwhelming. Conclusions: Research linking population need to available resources, and service models to services users' outcomes would be valuable in order to make clear recommendations on how mental health services can address the needs of this group more effectively.

## Introduction

The prevalence of learning disabilities among children aged 5 to 16 has been estimated at between 2.6% to 3.5% (Emerson, 2003, Emerson and Hatton, 2007). Given prevalence rates of mental health problems of 31% to 41% in children with learning disabilities (Dekker and Koot, 2003, Einfeld et al., 2006, Einfeld and Tonge, 1996, Emerson, 2003, Emerson and Hatton, 2007, Stromme and Diseth, 2000, Tonge and Einfeld, 2003), children with learning disabilities have been said to account for 14% of all children with mental health problems (Emerson and Hatton, 2007).

Policy documents and initiatives have a central function in ensuring that the mental health of children with learning disabilities is addressed at a national level (Lunsky et al., 2007). For example, in England and Wales, The National Service Framework Standards for the mental health and psychological well-being of children and young people include mental health services for children with learning disabilities in their markers of good practice for Standard 9: *'All children and young people with both a learning disability and a mental health disorder have access to appropriate child and adolescent mental health services'* (Department of Health and Department of Education and Skills, 2004). The Royal College of Psychiatrists Quality Improvement Network for Multiagency Child and Adolescent Mental Health Services (QINMAC CAMHS) developed standards that contain best practice statements and can help in the development of comprehensive child and adolescent mental health services that include children with learning disabilities (Dugmore and Hurcombe, 2007).

'Closing the GAP' in the USA proposed a blueprint to improve the health of adults and children with learning disabilities and to include them fully in health systems (U.S. Public Health Service, 2001). Some of the goals included in the blueprint were to improve the quality of health care and to produce good health outcomes for adults and children with

learning disabilities. The National Plan on Action for Children in Serbia includes as one of its priorities the improvement of the position of children with disabilities (Ispanovic-Radojkovic and Stancheva-Popkostadinova, 2011). The European Association for Mental Health in Mental Retardation adopted the Declaration of Rome 2003 (Seidel, 2004). This is a policy statement promoting awareness of mental health aspects and special needs of people with learning disabilities, and to raise the level of participation in service development among public policy makers, administrators, politicians, professionals, researchers, and relatives or friends of people with learning disabilities (Seidel, 2004). The European Manifesto on Basic Standards of Health Care For People with Intellectual Disabilities serves as a stimulant for governments, organizations, and individuals to work collectively to improve health care provision, including mental health, for people with learning disabilities throughout Europe (Meijer, Carpenter and Scholte, 2004).

These examples of policy and initiatives all promote better mental health services for children with learning disabilities. It has been established that there is a high prevalence of mental health problems among children with learning disabilities, but the extent and effectiveness of services have not been systematically assessed and views of service users have rarely been collected (McCarthy and Boyd, 2002). The aim of the current paper was to review existing research into mental health services for children with learning disabilities, in order to identify what is known about provision of mental health services for children with learning disabilities and what has been experienced as effective or challenging in providing good services.

### **Method**

A scoping review was carried out using the methodology outlined by Arskey and O'Malley (2005). The research question was to broadly identify what research had been conducted into mental health services for children with learning disabilities and more specifically to identify

what had been experienced as effective or challenging in providing good services. Scoping reviews provide a narrative or descriptive account of available research without the quality appraisal and synthesis of systematic reviews, in order to include a wide breadth of relevant studies (Arskey and O'Malley, 2005). A literature search was conducted using the Psycinfo, Medline, Embase and Social Care Online databases. Search terms included terms for learning disabilities (learning disability, intellectual disability, mental retardation, developmental disability, developmental delay) combined with 'child(ren)' or 'adolescent(s)' and 'mental health service(s)' covering all years. The search was restricted to materials published in English. The databases produced 106, 373, 366 and 73 hits respectively.

All publications that included information on mental health care or mental health services for children or adolescents with learning disabilities were included in the final selection. Publications were excluded when they did not focus on mental health, when they concerned adults rather than children, or when learning disability was not included in the study. Cited reference searches were carried out in Web of Science on selected papers and their reference lists were examined to identify additional studies. The final selection included 34 papers. The majority were papers from peer reviewed journals in addition to nine reports and two book chapters. The publications used a variety of methods, including mapping exercises, secondary data analysis, reviews of epidemiological data, literature reviews, and qualitative and quantitative studies. The following countries were covered by the publications: England, USA, Australia, Canada, South Africa, Greece, the Netherlands, Serbia, Bulgaria, Mexico, Italy and Germany.

## **Findings**

### **Models of Mental Health Care for Children with Learning Disabilities**

Four different models of mental health care for children with learning disabilities have been proposed in the literature, each with their own advantages and disadvantages (Berney,

2000, Foundation for People with Learning Disabilities, 2005, Gangadharan, Bretherton and Johnson, 2001, Williams and Wright, 2010). A lifespan model of learning disability services is how provision historically was arranged. These are all-age services and have the advantage of continuity of care and the possibility of close links with other learning disability services, but there is a risk of isolation and it is difficult to liaise with specialist child services (Berney, 2000, Gangadharan, Bretherton and Johnson, 2001, Williams and Wright, 2010, Wright, Williams and Richardson, 2008). A stand-alone learning disability specialist child and adolescent mental health service has the advantage of greater expertise and resources, but needs a large catchment area (Berney, 2000, Williams and Wright, 2010) and might not be as accessible and affordable as generic child and adolescent mental health services (Wright, Williams and Richardson, 2008).

Generic child and adolescent mental health services providing for children with learning disabilities have greater depth of specialist knowledge, the possibility of joint training and working, better links with non-learning disability services (such as child health) and service users have access to all services available, but it can be difficult to cope with the wider range of populations, problems and techniques (Berney, 2000, Williams and Wright, 2010, Wright, Williams and Richardson, 2008). A final model of care is a small specialist child learning disability team within generic child and adolescent mental health services that manages the most complex cases among children with learning disabilities (Foundation for People with Learning Disabilities, 2005). This team resources generic child and adolescent mental health services to care for those with learning disabilities accessing their services. This final model is a more recent development. Its single entry system ensures greater flexibility between specialist areas and greater access to the full range of generic child and adolescent mental health services (Foundation for People with Learning Disabilities, 2005).

Children with learning disabilities and mental health problems often fall between services, leaving community services to manage their mental health (Gangadharan, Bretherton and Johnson, 2001). Currently, there is no indication as to what service models overall lead to better outcomes for children with learning disabilities. The following section will first provide an overview of some of the progress and challenges in the current development of mental health services for children with learning disabilities. The remainder of this paper will then review research assessing views of service users and providers of mental health services for children with learning disabilities to identify what aspects of services have been experienced as useful or not.

### **Progress and Challenges in the Development of Services**

There have been developments in mental health services for children with learning disabilities in the past years, alongside recognised challenges. For example, annual reviews of child and adolescent mental health services in England show that the number providing services for children with learning disabilities has steadily increased from 48 in 2003, 62 in 2004, 68 in 2005, 85 in 2006, 94 in 2007 to 112 in 2008 (Barnes, Appleby and Parker, 2006, Barnes et al., 2009, Barnes et al., 2010, Barnes et al., 2007, Barnes et al., 2005, Barnes et al., 2006, Glover et al., 2004, Wistow and Barnes, 2009). The percentage of local authorities in England providing fully comprehensive mental health services for children with learning disabilities and mental health needs has also increased (3% in 2005; 25% in 2006; 39% in 2007; 42% in 2008), but 55% of local authorities only had plans and protocols with some services in place in 2008 (Barnes, Appleby and Parker, 2006, Barnes et al., 2009, Barnes et al., 2010, Barnes et al., 2007, Barnes et al., 2006, Wistow and Barnes, 2009). In Canada, there are no national requirements or guidelines on how to best meet the needs of individuals with learning disabilities and their families (Lunsky et al., 2007). A survey among key



informants pointed out that assessment or diagnostics and community mental health teams were available to less than half of children with learning disabilities (Lunsky et al., 2007).

In Serbia, a network of developmental counselling services has been developed in response to the mental health needs of children with learning disabilities (Ispanovic-Radojkovic and Stancheva-Popkostadinova, 2011). Multidisciplinary staff in these services have received training in prevention and early intervention for children with disabilities. However, there are no specialised inpatient mental health units in Serbia and outpatient mental health units are underdeveloped for children with learning disabilities (Ispanovic-Radojkovic and Stancheva-Popkostadinova, 2011). Mental health care for people with learning disabilities in Greece has changed from in-patient asylum-based treatment to community based services (Anagnostopoulos and Soumaki, 2011). However, no specialised mental health services have been developed for this group (Anagnostopoulos and Soumaki, 2011). Similarly, specialised child and adolescent mental health services dedicated to specific conditions such as learning disabilities are available only in some areas of Italy (Pedrini et al., 2012).

In Mexico, there are a great number of organisations providing learning disability services to children. However, these are non-governmental groups that are regarded as working from a philanthropic and charitable context rather than working from scientific evidence (Katz, Marquez-Caraveo and Lazcano-Ponce, 2010). In South Africa, policies are in place on the inclusion of people with learning disabilities and the National Mental Healthcare Act, which addresses the rights of mental health care users, includes people with learning disabilities (Adnams, 2010). However, mental health care needs of people with learning disabilities still go unmet due to policy not being effectively implemented (Adnams, 2010). Overall, these papers show that major developments in mental health services for children

with learning disabilities have been made in the last 14 years. However they also indicate that many challenges to providing effective mental health care for this group remain.

### **Difficulty Accessing Services**

Several studies have shown that children with learning disabilities may not be accessing the mental health services that they need. A study in the Netherlands asked parents of 289 children with learning disabilities, who perceived their child's emotional or behavioural functioning as problematic, about their support needs (Douma, Dekker and Koot, 2006). Of those parents who indicated that they needed either child mental health care or parental counselling due to the child's emotional and/or behaviour problems, only 40.6% and 35.5% respectively reported that this need was met. A study in Germany found that 22.5% of parents of children with a range of disabilities (including 59.7% with learning disabilities or developmental delay) needed advice on educational or behavioural problems, but did not receive it (Thyen et al., 2003). Both unmet psychosocial needs and the child having learning disabilities were found to be related to increased social disruptions, personal strain, financial strain, and concerns for siblings.

Similarly, in the USA among a sample of 149 caregivers of children with learning disabilities, 78% were aware of the availability of mental health services and 52% had used mental health services (Samuel et al., 2012). However, 22% of families in Samuel et al.'s study (2012) reported that they needed more mental health support, which was the fourth most frequently needed service after occupational, physical and speech therapy, education and respite care. When compared to children with physical disabilities and children with mental health problems, children with developmental disabilities have been identified as experiencing most difficulty using health care services (Nageswaran et al., 2011). This difficulty increases for children who have both developmental delays and mental health problems. In addition to this, within a population representative sample of children and young

people with learning disabilities in New South Wales and Victoria in Australia it was found that only ten percent of those with mental health problems received specialist mental health interventions (Einfeld et al., 2006). These studies suggest that there may be significant barriers to accessing services for children with learning disabilities.

Further research suggests that families from minority ethnic communities may experience additional difficulties in accessing appropriate services. South Asian families in the United Kingdom have been found to use child and adolescent mental health services significantly less for their child with a learning disability than white British families (Durà-Vilà and Hodes, 2009). It has been suggested that South Asian ethnic groups have higher proportions of multi-adult households and therefore would have a lower need for support from services (Durà-Vilà and Hodes, 2009). Some parents of South Asian origins have, however, identified this as a popular myth amongst professionals that they have to battle with in order to gain access to services (Faust and Scior, 2008). Alternative explanations for South Asian families' lower use of services are cultural inappropriateness of the services or language barriers (Durà-Vilà and Hodes, 2009).

Three types of barriers to accessing child mental health services in general have been suggested. First, structural barriers include a lack of availability of providers, long waiting lists, transportation problems or inconvenient services (Owens et al., 2002). Second, there are barriers related to perceptions of mental health problems such as an inability to identify children's need for mental health services, denial of the severity of mental health problems, or the belief that the problem can be handled without treatment (Owens et al., 2002). Finally, perceptions about mental health services can be a barrier, for example a lack of trust in or negative experience with mental health providers, and stigma related to receiving help (Owens et al., 2002). These barriers are also relevant for children with learning disabilities and mental health problems and these have been summarised in Textbox 1.

Textbox 1 *Barriers for children with learning disabilities and their families to accessing child mental health services.*

### **Structural constraints**

- Parents do not know where they can get help and information provision is experienced as poor (Douma, Dekker and Koot, 2006, Faust and Scior, 2008, Samuel et al., 2012, Wodehouse and McGill, 2009)
- Fragmentation of services and complexity in how services are organised contribute to difficulties in using services (Nageswaran et al., 2011, Thyen et al., 2003, Wilkins et al., 2010).
- A lack of resources is a barrier for mental health providers in meeting the needs of young people with learning disabilities and mental health problems (e.g. a lack of residential placements, lack of respite and meaningful and safe leisure opportunities and lack of expertise and skilled staff) (Scior and Grierson, 2004).
- Due to lack of inpatient specialist services, young persons with learning disabilities are admitted to inappropriate mainstream psychiatric services, often a long distance from the family (Faust and Scior, 2008, Scior and Grierson, 2004).

### **Perceptions of mental health problems**

- Stigma and shame attached to mental health problems creates difficulty for some parents to seek help for their child's mental health problems (Faust and Scior, 2008).
- Due to the complexity of mental health problems both parents and professionals experience difficulty and confusion in identifying what the problem is (Faust and Scior, 2008, Scior and Grierson, 2004).
- Again, due to the complexity of the experienced mental health problem, it can be unclear to identify what the role of different services is and families and children are not referred to the appropriate service (Betz et al., 2004, Faust and Scior, 2008, Scior and Grierson, 2004).

### **Perceptions of mental health services**

- When parents ask for help, many feel like they are not being taken seriously, feel they are being blamed for the child's behaviour or feel labelled as being neurotic (Faust and Scior, 2008, Wodehouse and McGill, 2009).
- Parents feel that a crisis needs to be reached before appropriate services are offered to them (Faust and Scior, 2008, Wodehouse and McGill, 2009) or that they have to battle with services before help is offered (McGill, Papachristoforou and Cooper, 2006, Wodehouse and McGill, 2009).

## **Negative Experiences of Services**

A number of studies have assessed parents' experience of services for their child's mental health problems or their experience of professional support for challenging behaviour. When parents were offered support (the type of support was not further specified in the studies), they felt that services were inadequate or inappropriate, were not taking the person's abilities into account and found that professionals were not always appropriately trained (Faust and Scior, 2008, McCarthy and Boyd, 2002, McGill, Papachristoforou and Cooper, 2006, Samuel et al., 2012, Wodehouse and McGill, 2009). Carers felt there was a lack of practical support and insufficient help to the family (McCarthy and Boyd, 2002, McGill, Papachristoforou and Cooper, 2006). The number of different services with different attitudes and ethos were experienced as overwhelming for parents and service users (Faust and Scior, 2008, Scior and Grierson, 2004). Being involved with a large number of services can be an additional source of stress for young people with learning disabilities and mental health problems and this flags up the need for a more multi-disciplinary approach (Scior and Grierson, 2004). Additionally, professionals have indicated that there can be a lack of communication and information sharing between different services and that this can result in significant risk, for example when medical personnel do not share vital information with educational providers (Scior and Grierson, 2004).

In a sample of 66 parents of children with learning disabilities, 36% found none of the psychological advice or treatment offered for their child's challenging behaviour helpful (McGill, Papachristoforou and Cooper, 2006). Similarly, 36% did not find the medication their child received helpful. Communication advice or treatment was not perceived as helpful by 23% of parents. Overall, 66% of parents were dissatisfied with medical help for challenging behaviour, 66% of parents were dissatisfied with psychological advice regarding challenging behaviour and 53% were dissatisfied with help regarding their child's

communication skills. Again, the specific support, service or medication accessed by these parents was not specified. In addition, the authors acknowledge that recruiting parents through a charity that provides support for challenging behaviour may result in a study sample where views of parents who felt their child's needs were not met are over-represented (McGill, Papachristoforou and Cooper, 2006).

The transition period from late adolescence into adulthood has been identified as a time of heightened risk for developing mental health problems (Blacher, 2001). However, the majority of young adults with learning disabilities and mental health problems were found to receive no specialist mental health services during the transition into adult services (McCarthy and Boyd, 2002). Transition can be particularly complex for individuals with mild to moderate learning disabilities as they might not meet criteria for learning disability services or adult mental health services but do require on-going support (Singh, 2009). Poor transition can lead to disengagement from services for those who do have on-going needs (Singh, 2009).

### **Positive Experiences of Services**

Despite these barriers and negative experiences, positive experiences of mental health services for children with learning disabilities have been also reported by parents, carers and service users. Children aged 11 to 17 with moderate learning disabilities who had received input from mental health services were asked about their experience with the service (Boyden, Muniz and Laxton-Kane, 2013). What they experienced as positive were the smaller personal things, such as handshakes, humour, smiles and talking about interests the first time they met the professional. The use of creative and interactive tools such as books, pictures, play dough or drawings to communicate feelings and thoughts was valued. They felt their problems had been addressed and felt they had changed as a result of the support.

Parents of 16-25 year old young adults with learning disabilities and current or past mental

health problems reported that help provided by services for their child's mental health problems was valuable, crucial to their survival and that they felt properly listened to (Faust and Scior, 2008). Similarly, in a retrospective study assessing service use, the majority of carers were satisfied with the mental health care provided for their then adolescent child (McCarthy and Boyd, 2002).

### **Implications for Advances in Practice**

The main challenge for parents trying to access services seems to be a lack of information on where to get help and not being referred to appropriate services. This can be due to the fragmentation and complexity of services and the complexity of the child's mental health problem. When parents do access services, the involvement with the number of services can be overwhelming and a lack of communication between services can be a problem. Parents of children with learning disabilities have suggested needing a clearer care pathway, more publicly available information on sources of help and a single point of access to help (Faust and Scior, 2008). To alleviate a sense of isolation, it would be helpful if there were opportunities to meet other parents in similar situations (Faust and Scior, 2008). In line with this, behaviour support by means of group training courses with other parents, would be beneficial (Wodehouse and McGill, 2009). Parents have advocated for partnerships with service providers rather than being regarded as consumers of a service, maintaining that parents and professionals should be equal partners and that service providers need to acknowledge and appreciate the skills that parents have (Knox et al., 2000). Some minority ethnic communities may experience difficulty accessing mental health services for their child with learning disabilities (Durà-Vilà and Hodes, 2009, Faust and Scior, 2008). Further research is needed to fully understand the reasons for this, but it is important that culturally appropriate services are available and accessible.

Children with learning disabilities and mental health needs felt that it is important for them to have a choice about where they are meeting professionals (Boyden, Muniz and Laxton-Kane, 2013). Some prefer to have appointments at school or at the clinic but others prefer to meet at home so the family can be involved (Boyden, Muniz and Laxton-Kane, 2013). Communication should be at a level appropriate to the child, there should be an open, welcoming approach (Boyden, Muniz and Laxton-Kane, 2013). Of the studies included in this review, only two have investigated the views of those who were in direct receipt of the service, i.e. Boyden, Muniz and Laxton-Kane (2013) and McCarthy and Boyd (2002). This indicates a need for further research to include the views of children and young people with learning disabilities themselves.

Service providers have expressed the view that having personal contact between professionals, e.g. frontline services and specialist health services, and having a named person to contact would make it easier to discuss concerns and to respond early when there is a reason to suspect mental health problems (Scior and Grierson, 2004). A lack of resources seems to be the main barrier for mental health services to meet the needs of children with learning disabilities. Both information on available services from mapping exercises and experiences of service users and providers highlight a lack of staff and a lack of availability of services, including inpatient services. A lack of resources can act as a barrier for staff to meet the needs of service users. In relation to this, a lack of expertise was identified by parents and staff. In addition to not meeting needs, this lack of resources, staff, services and expertise could also add further to the perception of services as not being able to offer appropriate help.

The reason for the lack of resources available for mental health services for children with learning disabilities could be related to past perceptions of children with learning disabilities as not worth investing in (Dugmore and Hurcombe, 2007). Mental health services



were therefore lacking and only since recent policy changes and initiatives has this changed. However, the development of services has been patchy, unplanned and dependent on local circumstances (Dugmore and Hurcombe, 2007). Services consequently vary widely. To improve access to child and adolescent mental health services for children with learning disabilities, the interface between the various tiers needs to be investigated along with a collaborative and holistic approach involving commissioning, design, delivery and review (Pote and Goodban, 2007, Sin, Francis and Cook, 2010).

### **Conclusions**

The high rate of mental health problems among children with learning disabilities in combination with the limited availability and appropriateness of child and adolescent mental health provision highlights the need for the development of services. This paper has identified four contemporary models of service provision, including a life span model and small specialist teams. The research reviewed here indicates what aspects of services could be improved or are experienced as positive, but does not provide any evidence as to what specific models of care would be more appropriate and would lead to better outcomes for this population. To allow this, further research is needed linking specific service models to service users' outcomes. In addition, while a lack of resources is frequently identified as a barrier in providing appropriate services, the link between population need and available resources remains unclear.

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